Submission No 100

INQUIRY INTO EQUITY, ACCESSIBILITY AND APPROPRIATE DELIVERY OF OUTPATIENT AND COMMUNITY MENTAL HEALTH CARE IN NEW SOUTH WALES

Organisation: Dementia Law Network

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Submission to the NSW Parliamentary Inquiry into the equity, accessibility and appropriate delivery of outpatient and community mental health care in New South Wales

6 September 2023

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1. We are co-founders of the Dementia Law Network: www.dementialawnetwork.org/. This Network brings together researchers, clinicians, legal practitioners, people living with dementia, their families and the broader community to advance knowledge on issues at the intersection of law and dementia.

2. Our submission concerns topic (i) of the Inquiry Terms of Reference: "alternatives to police for emergency responses to people experiencing acute mental distress, psychosis, delirium, dementia or intoxication in the community, including but not limited to Police, Ambulance, Clinical, Early, Response (PACER)."

3. In particular, our submission focuses on the problem that the **behavioural symptoms of dementia** may be perceived as criminal offending and result in contact with police and the criminal legal system. This contact can lead to inappropriate responses that are criminalised and punitive in nature and cause individual and societal harms.

4. Our submission is informed by a **stakeholder workshop** we convened in June 2023 at the University of Technology Sydney to address how we might we better recognise and respond to criminal risk issues for people with dementia in community settings. The workshop involved representatives from: NSW Police; Legal Aid NSW; Seniors Rights Service; Crime Stoppers NSW; NSW Ageing & Disability Commission; NSW Government, Department of Communities & Justice and Department of Health; Carers NSW; Dementia Support Australia; City of Sydney (Access & Inclusion); and health professions, including neuropsychology, psychiatry, general practice, and community and aged care nursing.

5. The Workshop Report forms an **integral part of our submission**: Nola Ries, Sascha Callaghan & Fiona Kumfor, *Criminal risk behaviours in people with dementia - Stakeholder Workshop Report* (University of Technology Sydney, 2023) DOI: https://doi.org/10.57956/e24z-n211. The Workshop Report is attached to this submission.

6. The workshop discussions underscored the importance of adopting **non-criminalising approaches** to people who live with dementia. The following priorities were identified:
    a. improving awareness and recognition of behavioural changes that may indicate dementia or that emerge in the context of dementia;

b. improving access to appropriate services and support for individuals and their carers; and
c. reducing the overreliance on police as first responders.

Behaviour changes in the context of dementia – our research findings

7. Behaviour changes are common across subtypes of dementia. These may include changes in a person's ability to reason and make judgements, understand and abide by social norms, understand and empathise with others and inhibit inappropriate behaviour.

8. Some behaviours – such as verbal and physical aggression, social disinhibition and inappropriate sexual behaviours – may lead to contact with police and the criminal legal system. We refer to these behaviours as 'criminal risk behaviours.' Please see page 6 of the Workshop Report for a **continuum of behaviours**, which encompasses early signs of behaviour change, repeated or escalated behaviours, and serious and violent behaviours.

9. There is limited research on the nature and prevalence of criminal risk behaviours in the context of dementia. Most of the literature has focused on case studies or retrospective case reviews; please see pages 7-8 of the Workshop Report for a summary of relevant international studies.

10. To overcome this gap in knowledge in Australia, we developed a new tool to screen for criminal risk behaviours – known as the **Misdemeanours and Transgressions Screener** (MATS). The MATS is completed by an informant (typically a spouse or child) who spends at least five hours per week with the person living with dementia.

11. The MATS screens for criminal risk behaviours across 10 domains: i. traffic violations (e.g., speeding, driving without a licence), ii. stealing (e.g., stolen money, stolen car), iii. avoiding payments (e.g., not paying for a good or service), iv. verbal abuse, v. physical assault (another person or animal), vi. inappropriate behaviours (e.g., inappropriate sexual advances, hugged or kissed a stranger), vii. public indecency (e.g., urinated in public, masturbated in public), viii. property trespass or damage, ix. illegal drug use or supply, x. financial or professional recklessness (e.g., behaved unethically at work, developed a gambling problem).

12. To date, we have collected and analysed data from 144 people with dementia and 53 demographically-matched controls without dementia. Participants had been diagnosed with a range of dementia subtypes including: Alzheimer's disease, behavioural-variant frontotemporal dementia and primary progressive aphasia.

13. Irrespective of diagnosis, 47% of people with dementia reported at least one criminal risk behaviour.

14. Compared to adults without dementia, people with dementia showed higher rates of physical assault, including being physically aggressive to strangers in public settings, and intentionally hurting or being cruel to animals.

15. People with dementia were also more likely to show financial/professional recklessness. This included behaviours such as excessive spending, developing a gambling problem, falling for scams, donating large sums of money that was out of character, behaving unethically at work, cancelling insurance policies, online spending and making impulsive large purchases (>$1000 without a spouse's knowledge/consent).

16. People with dementia were also more likely to show inappropriate behaviours such as making sexual advances, touching, hugging or kissing strangers, approaching children they did not know, being overly friendly with strangers (e.g., offering massages) and making inappropriate comments (e.g., telling a screaming child to shut up, or asking questions about a person's virginity).

17. In our cohort, demographic factors (age, sex, education) did not predict whether a person would show a criminal risk behaviour or not. However, people with a diagnosis of behavioural-variant frontotemporal dementia were seven times more likely to show criminal risk behaviours than the other dementia subtypes. This variant of dementia affects areas of the brain that are involved in regulating behaviour, judgement and empathy. Longer disease duration was also associated with the presence of criminal risk behaviours.

18. Importantly, nearly 20% of people in our study who showed criminal risk behaviours had contact with the police or other authority figures, such as security personnel. The reasons for contact with police and authority figures were varied and included allegations or reports of perceived criminal offending, such as domestic violence, altercations with strangers, holding family members hostage, shoplifting, road rage and possessing and selling stolen goods. However, the person's dementia diagnosis meant that these situations did not necessarily involve an intention to commit a criminal offence. Police or other authorities were also involved in situations where a person with dementia absconded from residential care or was reported missing/lost/wandering.

19. The contact with police or other authority figures had a range of consequences for people with dementia. For example, some people were banned from public places (e.g., sports clubs, shopping centres), received police warnings/cautions, were subject to domestic violence orders, or were detained, held in custody or charged with offences. Some people were admitted to hospital, including being scheduled in psychiatric wards.

20. We have also conducted research interviews with family members/carers of people with dementia, primarily people with younger onset frontotemporal dementia (where symptom onset occurs before age 65). Family carers expressed concern about the risk of negative responses to their family member with dementia, including risk of unsupportive contact with security guards and police, or other people in the community reacting to the person with dementia in hostile ways.

21. Family carers felt that negative responses were linked, in part, to a lack of community awareness of younger onset dementia and the behavioural signs and symptoms of dementia. Family members also described situations where police involvement escalated a difficult situation and called for better use of de-escalation strategies.

22. Family carers described limiting opportunities for the person with dementia to participate in the community (e.g. restricting their social activities) to reduce the risks of difficult situations that could lead to police involvement. However, such limitations contributed to social isolation for the person with dementia and increased carer stress.

23. Our research data reflects a cohort of people with a formal diagnosis of dementia who are under regular care of health professionals. Where they have been charged with offences, they have mostly had the support and resources needed to avoid prosecution, including by submitting medical evidence of their diagnosis and symptoms. Other people are more vulnerable to criminalised responses and consequences, including those displaying pre-diagnostic behaviour changes, people with co-morbid conditions (e.g. mental health and/or substance use disorders), people from minoritised groups and in disadvantaged socioeconomic circumstances. All of these factors may create or exacerbate barriers to accessing medical, social and legal services.

Recommendations

24. Our research highlights the need for **health-focused responses** to criminal risk behaviours in the context of dementia. Key objectives are to improve earlier recognition of behavioural signs of symptoms of dementia, improve access to diagnostic and care pathways and avoid punitive, criminalised responses.

25. Our data from the MATS screening study suggest that the new onset of criminal risk behaviours in midlife or older is a red flag for a potential dementia aetiology and warrants medical investigation.

26. The Workshop Report recommends a number of **strategies to avoid the criminalisation of behaviours** in the context of dementia; please see pages 14-18.

27. In particular, recommendations to **reduce the reliance on police** as first responders are on pages 17-18.

28. Where police are involved, appropriate training, education and support is needed to ensure that the interaction does not have a negative effect on the person living with dementia. The PACER approach was highlighted by stakeholders as a good example of such an approach, yet has been limited with respect to scale and resourcing across areas.

29. Diversion of people from the criminal justice system and reducing police contact is likely to have benefits for people living with dementia and their families, while also reducing the economic burden and inappropriate use of police resources to manage health issues.

30. Further **investment in research** is essential to strengthen the evidence base in New South Wales about criminal risk situations that involve people with suspected or diagnosed dementia in the community. Please see page 19 of the Workshop Report for an agenda for research that spans a continuum of risk behaviours in dementia.

31. Through the Dementia Law Network we are keen to build collaborations and undertake research that advances knowledge in this field. We also note that the National Dementia Action Plan will provide a roadmap for improvements to policies, services and systems across various sectors. We are both members of the NSW Dementia 100 Expert Reference Group and we commend this initiative, which will inform actions in New South Wales in relation to the National Dementia Action Plan and Implementation Blueprints.

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